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People with Intellectual Disabilities' Experiences of Psychological Therapy: A  
Systematic Review and Meta-ethnography

**Abstract**

The effectiveness of a range of psychological models adapted for use with people with intellectual disabilities has been well documented. A number of studies have used qualitative methods to examine people with intellectual disabilities' experiences of these adapted interventions. Such research is important for identifying service users' views on the helpful and challenging aspects of psychological interventions to ensure they meet the needs of people with intellectual disabilities. To consolidate this research, a systematic review using a meta-ethnographic approach was undertaken. A systematic search identified sixteen relevant studies. These studies were reviewed, critically appraised and key themes were extracted. Five key concepts were identified: adapting to therapy, the therapeutic environment, group dynamics, the therapeutic relationship and the impact of therapy on life. The need for further consideration of power differentials within the therapeutic relationship and further adaptations to ensure accessibility of therapy for people with intellectual disabilities are discussed.

## Introduction

The prevalence of mental health difficulties amongst people with intellectual disabilities has been estimated at between 10 to 40 percent (Borthwick-Duffy, 1994; Deb, Thomas, & Bright, 2001; Cooper, Smiley, Morrison, et al., 2007), suggesting higher rates than in the general population (Singleton, Bumpstead, Brien, et al., 2003). Exact rates have been difficult to establish due to limited data and epidemiological studies which use different diagnostic criteria and assessment methods, small sample sizes, and different subpopulations. Negative life events and genetic vulnerability are thought to increase the likelihood of mental health difficulties in this client group (Clarke, 2003; Hulbert-Williams & Hastings, 2008). For instance, people with intellectual disabilities are at significant risk of abuse (Brownridge, 2006) and are exposed to a higher number of traumatic life events compared to the general population (Fenwick, 1994). However, despite a likely higher prevalence, there continues to be a relative dearth of literature looking at the experiences of mental health difficulties for people with intellectual disabilities. This may be due to the historical exclusion of people with intellectual disabilities from research, historical assumptions that people with intellectual disabilities do not experience the same range of emotions as people without intellectual disabilities, diagnostic overshadowing where all difficulties were thought to be due to the intellectual disability, low attendance at primary care services which reduces opportunities for assessment, and a failure to discriminate between challenging behaviour and mental health difficulties (British Psychological Society, 2015). Treatment traditionally focused on pharmacological and behavioural approaches, because of assumptions that the cognitive difficulties associated with an intellectual disability would prevent engagement in psychological therapy (Adams and Boyd, 2010). However, a range of psychological models have now been adapted from the general population and applied to this client group. A recent report by the British Psychological Society reviews the use of such models in clinical practice, including adaptations to consider for this client group such as use of simple language, short sentences, non-verbal techniques, visual material, and role plays (British Psychological Society, 2015).

A number of studies have used quantitative methods to examine the effectiveness of adapted interventions. A recent meta-analysis by Vereenoghe and

Langdon (2013) suggests psychological therapy has an overall moderate effect for treating mental health difficulties in people with intellectual disabilities.

Effectiveness depended on therapy type and presenting difficulty. For instance, CBT interventions focused on anger were found to have a large effect size whilst group psychotherapy interventions focused on interpersonal functioning were not found to be effective. When CBT was excluded, there was no significant evidence regarding the effectiveness of other psychological therapies. In addition, attrition rates were variable but reasons for attrition were not consistently reported across studies. This review highlighted the need for additional, more robust research examining the effectiveness and experiences of psychological interventions for this client group.

Quantitative research exploring the effects of psychological therapy for people with intellectual disabilities tends to focus on outcomes, examining whether the symptoms of someone's mental health difficulties have reduced following psychological treatment. Qualitative research can complement quantitative measurement by exploring sensitive, complex experiences and attitudes (Pope and Mays, 1995). It is important to understand service users' perspectives on the process of therapy as well as the outcomes to be able to further understand reasons for attrition rates (Vereenoghe and Langdon, 2013) and to offer acceptable treatment options. This is further indicated in a meta-analytic review by Martin, Garske and Davis (2000) who found the therapeutic alliance was moderately related to therapy outcome. In line with this, Bordin's (1979) theory of the working alliance proposes treatment success depends on the working alliance between client and therapist. The working alliance involves a mutual understanding and agreement of therapy goals, completion of tasks aimed at moving towards these goals and an established bond to maintain this work. Such research gives further support to the importance of exploring the process of therapy as well as therapy outcomes.

Qualitative research in the general population has identified a number of themes related to helpful and unhelpful aspects of therapy (Elliott, 2008). The helpful aspects include: the therapist listening, providing reassurance, exploring difficult emotions, and being empathetic and validating. The development of a collaborative relationship is also valued (Llewelyn, 1988, Glass and Arnkoff, 2000). There is limited feedback on the helpful nature of specific therapeutic interventions, although offering specific techniques for dealing with problems has been reported as

valuable (e.g. Berg, Raminani, Greer et al., 2008). Unhelpful aspects of therapy include: the therapist being judgmental or invalidating, making assumptions, showing a lack of respect and a reluctance to explore difficult areas (Glass and Arnkoff, 2000; Llewelyn, 1988). This research highlights the importance of aspects of the process of therapy for people who are engaging in therapy. This is supported by the findings of quantitative research, which has demonstrated an association between outcomes and several aspects of the therapeutic alliance including a collaborative relationship, empathy, positive regard and genuineness from the therapist (Norcross, 2002). Qualitative research can therefore provide insight into service users' overall satisfaction with a type of therapy as well as clients' views of positive and negative aspects of the process (Khan et al., 2007). This is particularly relevant for people with intellectual disabilities who have traditionally not been provided with opportunities to discuss their therapy experiences (Hoole and Morgan, 2010).

Although the themes identified above may well be relevant for people with an intellectual disability, it cannot be assumed they will have the same experience of psychological therapy as people without an intellectual disability. The social exclusion of people with intellectual disabilities has been well documented (Department of Health, 2001). The social model of disability emphasises how barriers, negative attitudes and exclusion by society can contribute to disabling a person (Hasler, 1993). As people with intellectual disabilities may have had such experiences, they may not have had many previous opportunities to talk about themselves and their feelings. Thus, people with intellectual disabilities may find it more difficult to access and engage with therapy; potentially impacting on their experience of psychological interventions. Furthermore, although there is guidance on the adaptations that should be made for engaging people with intellectual disabilities in psychological therapy (British Psychological Society, 2015), it is important to seek people with intellectual disabilities' views on whether such adaptations were accessible for them during therapy.

Preliminary searches suggested that a number of studies using qualitative methodology to gain feedback on people with intellectual disabilities' experiences of therapy have recently been conducted.

The aims of this review were therefore:

- 1) To systematically identify and appraise the quality of qualitative studies regarding the experiences of psychological therapy for people with intellectual disabilities.
- 2) To use meta-ethnography to synthesise the results of the identified studies.

## **Method**

### **Design**

The method of this literature review involved three stages: (1) a systematic literature search, (2) quality appraisal of the selected studies, and (3) a meta-ethnography synthesis, as developed by Noblit and Hare (1988) and adapted for health research as described by Britten et al (2002).

### **Search method**

Web of Science, PsychInfo and PubMed were used to conduct a literature search for all peer reviewed, primary research papers in ‘all years’ relating to experiences of individual or group-based psychological therapy for people with intellectual disabilities. Studies had to meet the following criteria: (i) be published in English in a peer-reviewed journal; (ii) use qualitative methodology; (iii) involve a psychological intervention aimed at the treatment of emotional, behavioural or mental health problems; (iv) involve participants aged 18 years or older with a diagnosed intellectual disability in accordance with the DSM-IV criteria (American Psychiatric Association, 2000) or ICD-10 (World Health Organization, 1992). Studies involving mixed methods which met the above criteria were included if detailed information was given on the qualitative methodology and findings. Table 1 lists the search terms that were used.

Table 1.

Search terms used in the systematic review of the literature.

Search term	Variation
Intellectual disability	“Intellectual* disab*” OR “learning disab*” OR “mental* disab*” OR “mentally disabled” OR “cognitive* disab*” OR “mental* retard*” OR “mental* handicap*” OR “mentally handicapped” OR “mental* deficien*” OR “learning difficult*”
Psychological therapy	“Psycho* therapy” OR “Psycho* treatment” OR “Psycho* intervention” OR “Psychotherap*” OR “psycho-therap*” OR “therap*”
Service user experience	“Service user experience” OR “Service user views” OR “Experiences” OR “Views” OR “Satisfaction” OR “attitudes” OR “Perceptions” OR “Client attitudes” OR “Patient Satisfaction” OR Therapeutic process* OR Psychotherapeutic Process*
Qualitative research	“Qualitative research” OR “Qualitative method*” OR “Thematic analys*” OR “Interpretative Phenomenological Analys*” OR “Grounded Theory*” OR “Discourse Analys*” OR “Content Analys*”

A literature search was conducted on 9<sup>th</sup> February 2018. The process for identifying eligible articles is illustrated in Figure 1.

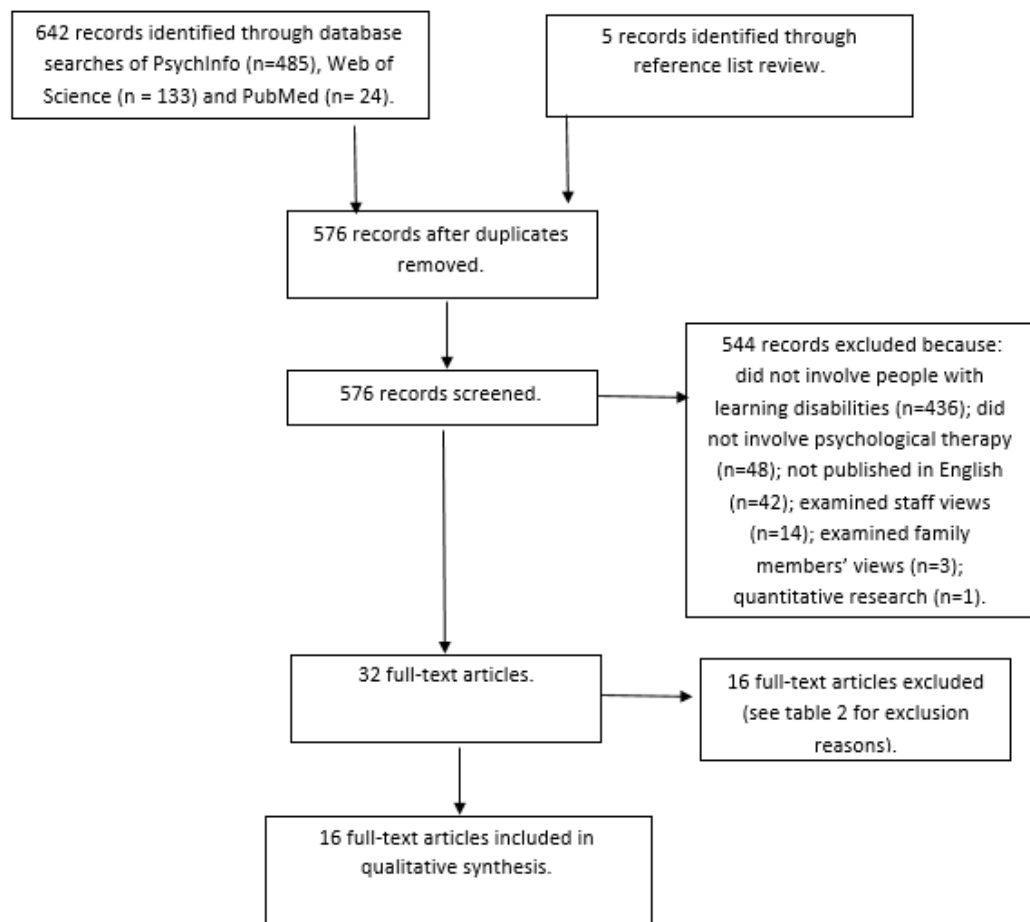


Figure 1. PRISMA flow diagram of search outcomes.

Table 2.

A record of the reasons for excluding full-text articles retrieved from the systematic literature search.

Reason for paper exclusion	Number of papers this applied to
Not focused on people with intellectual disabilities experiences of psychological therapy	13
Involved children or adolescents with an intellectual disability	2
Review paper	1



**Study characteristics**

Table 3 outlines the characteristics of the included studies. Ten of the papers included in this literature review used solely qualitative methodology (2, 6, 7, 8, 9, 11, 12, 13, 14, 16). Six papers used mixed methods, incorporating a qualitative component using semi-structured interviews (1, 3, 4, 5, 10, 15). It was decided to include the qualitative results from mixed methods papers as detailed information was given on their qualitative methodology and findings. Sample sizes ranged from 3 to 20 and included 71 males and 48 females, although three of the studies did not state the gender of participants (24 participants in total whose gender was unknown). Included studies had all been conducted in the UK. Six of the studies used cognitive behavioural therapy (CBT) either individually or in a group setting, three studies used a psychodynamic model, three studies used dialectical behaviour therapy (DBT) and one used compassion focused therapy (CFT). Three studies did not state the models used, which limits comparisons that can be made across models. Six studies involved group based therapy, seven involved individual therapy and two used a full DBT programme, which involves both individual and group treatment.

Four of the included studies (4, 8, 11, 13) used full scale IQ to confirm the level of intellectual disability of participants. Full scale IQs indicated that participants within these studies had a mild or moderate level of intellectual disability. Four studies indicated participants had mild intellectual disabilities and two studies reported participants had mild to moderate intellectual disabilities (1, 3, 4, 9, 12, 15). However, these studies did not screen participants to confirm this. The remaining studies did not comment on the level of intellectual disability of participants. Although all participants were recruited from intellectual disability services, the lack of screening of level of intellectual disability is a limitation as this increases the risk of inclusion of people who may not meet criteria for a diagnosis.

Table 3. Study characteristics.

Study number	Source Paper	Number of service users	Sample characteristics	Method of data collection	Intervention type	Aim
1	Crossland, Hewitt & Walden (2017)	4	3 females, 1 male. Aged 24-48.	Individual semi-structured interviews. Mixed methods.	18 week DBT skills training group.	To evaluate the DBT group.
2	Gifford, Evers & Walden (2013)	8	2 females, 6 males. Aged 27-46.	Individual semi-structured interviews.	Individual psychological therapy.	To investigate what is helpful and what is not helpful to people with intellectual disabilities about working with clinical psychologists.
3	Hardiman, Willmoth & Walsh (2018)	3	2 females, 1 male. Aged 31-48.	Individual semi-structured interviews.	Individual CFT. 12-15 weeks.	To investigate the effects of a CFT intervention.
4	Hassiotis et al (2013)	13	Gender and age unknown.	Individual semi-structured interviews.	Individual CBT for mood disorders. 16 weeks.	To investigate the acceptability of the sessions for service users and clinicians.
5	Hays, Murphy, Langdon, Rose & Reed (2007)	16	16 males. Aged 20-61.	Individual semi-structured interviews.	Group CBT for individuals with an LD who have sexually offended. Ran for 1 year.	To gather the views of people with intellectual disabilities who have sexually offended of a CBT group.
6	Khan and Beail (2013)	20	12 men, 8 women. Aged 17-64.	Individual semi-structured interviews.	15 participants had psychodynamic therapy, 2 participants had integrative counselling and 3 participants had CBT.	To measure service user satisfaction with individual psychological therapy delivered in an out-patient setting.
7	Lewis, Lewis & Davies (2015)	6	5 females, 1 male. Aged 20-43.	Individual semi-structured interviews.	Individual psychological therapy with a clinical psychologist or a trainee clinical psychologist which	To explore the individual experiences of service users with an intellectual disability who have accessed

					had ended no more than 6 months ago.	direct psychological therapy.
8	MacDonald, Sinason & Hollinsal (2003)	9	4 men, 5 women. Ages unknown.	Individual semi-structured interviews.	Two groups based on psychodynamic group psychotherapy. One group was a sexual offenders group and one was a woman's group. The four male participants had been attending the group for over a year. The five female participants had been in the group for 2-8 months.	To elicit clients' views on their experience of group analytic therapy.
9	MacMahon et al (2015)	11	8 men, 3 women. Aged 22-44.	Semi-structured individual interviews within 2 weeks of the last group session.	12 sessions of group CBT for anger management.	To provide opportunities for participants to express their opinions and discuss their experiences of the group.
10	Marwood and Hewitt (2012)	4	Gender and age unknown.	Individual semi-structured interviews. Mixed methods.	6 sessions of group CBT for anxiety.	To investigate the effectiveness of group CBT for individuals with an intellectual disability who experience anxiety.
11	Merriman and Beail (2009)	6	6 males. Aged 22-45.	Individual semi-structured interviews.	Individual psychotherapy for two or more years.	Aimed to ascertain service user's views on individual psychotherapy.
12	Pert et al (2013)	15	8 men, 7 women. Aged 26-52.	Two semi-structured individual interviews, lasting one hour each. The first interviews were carried out between the fourth and fifth therapy sessions. The second interviews occurred between the ninth and tenth session.	Individual CBT for a range of difficulties (Four clients were referred for depression, four for anxiety, four for anger and three clients had a mixed presentation).	To explore views of people with an LD who had engaged in individual CBT in order to establish what aspects of therapy were significant for each individual.

13	Ramsden, Tickle, Dawson & Harris (2015)	6	6 males. Aged 19-43. Recruited in the UK.	Individual semi-structured interviews.	Individual psychological therapy completed within the last 3 months.	To explore facilitators of and barriers to positive therapeutic change.
14	Roscoe, Petalas, Hastings, & Thomas (2015)	10	10 women. Aged 19-57.	Individual semi-structured interviews.	DBT programme. Participants had been receiving DBT for varying lengths of time (between 3-23 months).	To explore experiences of DBT for female inpatient service users with an intellectual disability.
15	Stenfort Kroese et al (2016)	5	3 females, 2 males. Aged 21-46.	Individual semi-structured interviews. Mixed methods.	12 weeks of group trauma focused CBT.	To explore participants' experiences of the group intervention.
16	Thomson & Johnson (2017)	7	Gender and age unknown.	Individual semi-structured interviews.	DBT programme in an inpatient setting.	To explore women's experiences of DBT.

### Quality appraisal

The CASP checklist (Critical Appraisal Skills Programme, 2017) was used as a tool for appraising the quality of the papers. The aim of this appraisal was to determine whether the quality of the study affected the contribution of the study to the overall synthesis. No study was excluded based on its' quality appraisal but instead the appraisal process was used to test the contributions of the papers at a later stage. Table 4 outlines the scores of each paper for each of the quality appraisal criteria. Based on the approach of Dixon-Woods et al (2007), following use of the CASP checklist, each paper was evaluated as KP ('key paper' that is conceptually rich and could potentially make an important contribution to the synthesis); SAT (a satisfactory paper); or '?' (when the reviewer is unsure of its relevance or value to the synthesis). Eleven of the papers were evaluated as KP, four papers were evaluated as SAT and one paper was evaluated as '?'. Studies judged as being of a poorer quality did not involve rigorous data analysis, did not provide sufficient details as to the consent procedures, which is of particular importance when involving people with intellectual disabilities in research, and did not explicitly consider the relationship between researcher and participant and how this may have impacted on the findings. Issues of power are particularly pertinent when working

with people with intellectual disabilities and so the researcher-participant relationship should be considered when conducting research in this field.

Table 4.

Completed CAPS checklist.

Paper	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	Is the research valuable?	KP, SAT or ?
1	Y	Y	Y	Y	Y	N	N	Y	Y	Y	SAT
2	Y	Y	Y	Y	Y	Unclear	Y	Y	Y	Y	KP
3	Y	Y	Y	Y	Y	N	N	Y	Y	Y	SAT
4	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	SAT
5	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	?
6	Y	Y	Y	Y	Y	N	N	Y	Y	Y	SAT
7	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	KP
8	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	KP
9	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	KP
10	Y	Y	Y	Y	Y	Unclear	Y	Y	Y	Y	KP
11	Y	Y	Y	Y	Y	Unclear	Y	Y	Y	Y	KP
12	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	KP
13	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	KP
14	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	KP
15	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	KP
16	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	KP

### Synthesis

The synthesis of the literature used a meta-ethnographic approach (Noblit and Hare, 1988). Meta-ethnography is an interpretive method, which aims to develop new interpretations and conceptual insights (Noblit and Hare, 1988). As this review aimed to contribute to the theoretical understanding of people with

intellectual disabilities' experiences of psychological therapy, this approach seemed appropriate as it allows for preservation of the interpretive properties of the data. A meta-ethnography aims to develop 'third order constructs' from the 'second order constructs' used by the authors of the papers. As definitions of first, second and third order constructs can vary, table 5 shows the definitions used in this review, which draws on the work of Noblit & Hare (1988) and Britten et al. (2002):

Table 5.

Definition of first, second and third order constructs.

First order constructs	People with intellectual disabilities' views of their experiences of psychological therapy.
Second order constructs	The authors' views and interpretations (expressed in terms of themes and concepts) of people with intellectual disabilities' views on their experiences of psychological therapy.
Third order constructs	The views and interpretations of the synthesis team (expressed in terms of themes and key concepts).

### **Determining how studies are related and identifying second-order constructs**

The first step of the synthesis was to read the included articles in chronological order and to extract key themes and concepts as expressed originally by the participants (first order constructs) and authors (second order constructs). A table was used to document the second order constructs from each paper and raw data from the papers (first order constructs) which illustrated the second order constructs. Additional ideas which arose as papers were read were also noted. This aided with the development of third order constructs.

### **Translating studies into one another**

Once the first and second order constructs from each paper had been extracted, the next step involved translating the studies into one another. Translating within meta-ethnography refers to comparisons of themes, concepts and interactions of the studies whilst maintaining the central themes in the original studies (Noblit &

Hare, 1988). To do this, a grid was created in Microsoft 'Excel'. Each paper was entered into a separate cell and the second order constructs from each paper were entered into the rows of the grid. The row labels were in the authors' original words or a close paraphrase. A description of each second order construct was also included, to preserve the terms used in the papers. A translation of each second order construct across all papers was then possible by looking for key concepts across papers. Each cell of the grid was considered in turn to ensure the second order construct from each paper was encompassed. Reference was made to the first order constructs whilst doing so to understand the interpretation made of first order constructs by the authors of the papers. The outcome of this translation process is illustrated in table 6. Those papers in bold were rated at the critical appraisal stage as 'Key Paper' (KP). Removing papers not rated as 'KP' did not change the presence of second order constructs. During this process, a conceptual map was also drawn to visually represent the themes and subthemes (appendix 1).

Table 6.

Translation of second order constructs and resulting third order constructs.

<b>Third order construct</b>	<b>Second order construct</b>	<b>Papers that included the second order construct</b>
Adapting to therapy	The emotional impact of preparing for therapy	<b>2, 7, 9, 11, 15.</b>
	Accessibility of therapy	1, 3, 4, 6, <b>7, 9, 10, 13, 14, 16</b>
	Talking is helpful	<b>2, 5, 6, 7, 8, 9, 10, 11, 12</b>
	Talking can be distressing	<b>5, 7, 8, 12</b>
The therapeutic environment	Confidentiality	1, <b>2, 7, 11, 12,</b>
	Choice	1, <b>2, 4, 5, 6, 7, 10, 11, 13</b>
Group dynamics	Inclusion	1, <b>5, 8, 9, 10, 14, 15</b>
	Group composition	1, <b>8, 9, 10, 14, 15, 16</b>
The therapeutic relationship	Positive feelings towards therapist	<b>2, 3, 6, 7, 11, 13</b>
	Feeling listened to and valued	<b>2, 3, 4, 8, 12, 13, 15</b>

	Collaborative	<b>7, 8, 11, 12</b>
The impact of therapy	Positive impact on life	<b>2, 3, 4, 6, 7, 9, 11, 12, 15, 16</b>
	Use of new skills	<b>1, 3, 5, 7, 9, 10, 14, 16</b>
	Maintaining change	<b>1, 2, 4, 9, 12, 13, 15, 16</b>

### **Synthesising translations**

Finally, the translations were synthesised to determine how the studies were related to each other. Noblit and Hare (1988) proposed three potential types of synthesis: reciprocal, where concepts of one paper could readily encompass another; refutational, where concepts across papers are conflicting; and line of argument, where concepts across papers are taken together and interpreted as a ‘line of argument’. In this review a line of argument approach was used to compare interpretations, explore similarities and differences and integrate these to produce an overarching framework. A data-driven, inductive approach was used to analyse the data. Themes were coded at a semantic level using a realist approach to reflect the reality of participants’ experiences and to identify broader meanings across the data set (Braun and Clarke, 2006).

### **Reflexivity of the researcher**

It is important to recognise the researcher’s perspective to consider how this may have impacted on the research procedure and data interpretation. The lead author is a 27 year old female White British trainee clinical psychologist with a background of working with people with intellectual disabilities. This has impacted on her research interest within this area through wanting to promote the inclusion and empowerment of people with intellectual disabilities and to gain a deeper understanding of their experiences of psychological interventions. The researcher was aware of this and looked at the findings with an open mind as much as possible to try to avoid potential bias in the synthesis.



## **Findings**

From the synthesis, five key concepts were identified: adapting to therapy, the therapeutic environment, group dynamics, the therapeutic relationship and the impact of therapy on life.

### **Adapting to therapy**

#### **The emotional impact of preparing for therapy**

Therapy was initially highly anxiety-provoking, with participants talking of the nerves they felt prior to attending both group and individual session (2, 7, 9, 11, 15). This seemed to relate to anxiety about meeting new people and also anxiety due to not knowing what to expect from therapy.

#### **Accessibility of therapy**

Adaptations were made to therapy which seemed to increase accessibility. For example, one participant talked about how they had ‘done like a big project, we done like a big sea, like a back to the future timeline thing, but it was a sea thing. It had fishes like, from the start to the end of my past...’ (7). Such adaptations made therapy fun and enjoyable for participants (7, 9), which in turn is likely to have increased participants’ engagement in therapy.

The use of hand-outs and homework tasks also increased accessibility as it helped participants to remember and explain their feelings and difficulties (1, 4, 6, 10). However, for some participants the materials did not seem to be fully adapted to their needs, illustrating the importance of tailoring materials for the individual (1, 10, 16) whilst for others the concept of having homework checked was unpleasant (4). The role of support staff in increasing accessibility of therapy was highlighted. Some participants described how the support of staff both during sessions and with homework aided their understanding (1, 13) whilst others would have liked their staff to have more of an understanding of the treatment model (16).

Although adaptations seemed to increase accessibility of therapy and a number of participants demonstrated a good understanding of the treatment model,

making links between the content of therapy and its application outside of therapy was very difficult for some participants (10) as was understanding and remembering aspects of the treatment programme (1, 3, 13, 14). For instance one participant commented they “didn’t like the mindfulness bit...I didn’t understand that very well” (13). One participant also highlighted how the therapist ‘talked to me in drabs and talked too fast. I could only understand half the time’ (6), illustrating the importance of the therapist adapting their approach to increase accessibility for people with intellectual disabilities.

### **Talking is helpful**

Having space in therapy for the person to talk about their difficulties was seen as helpful. One participant stated it was ‘helpful that you can go somewhere and talk to someone about problems...’ (8) whilst another said ‘it felt great when I started talking to him and getting things off my chest which I’d done in the past to stop me doing it again. It was a great relief’ (11).

Participants also illustrated the beneficial effects of talking on their wellbeing. One participant stated ‘It’s like going in a great mood...talking to somebody’ (9) whilst another said ‘I feel a lot better, relaxed. I feel this great big weight come off my shoulders and I felt thingy, and that weight can stay away altogether and I feel a lot better’ (12). For some participants talking also had beneficial effects in terms of helping them to resist the urge to reoffend (8).

### **Talking can be distressing**

Although participants indicated that talking about their problems could be helpful, for some participants talking about difficult times in their past was very distressing, indicating that they previously would have avoided thinking about these experiences (5, 7, 8, 12). For instance, one participant indicated “[What do you think was the worst thing about meeting a psychologist?] Talking about the past....What I found hard was the time I had to think about the past, that is all” whilst another said “[What was the worst thing about meeting with the psychologist?] Having to open up, when you see them you have to open up a lot.” (6).

## **The therapeutic environment**

### **Confidentiality**

Participants highlighted the private, confidential nature of therapy and how this enabled them to feel more able to share their experiences. One participant said ‘I felt a bit more comfortable one to one, because you can talk about things that are private and confidential. Any, like...eh problems that you’ve got that you don’t want anybody else to know because it’s private, you know’ (12). Although participants seemed to value the confidential nature of therapy, some struggled when the psychologist met with their staff, expressing anxiety that they would be told off by their staff for what they had shared in therapy (7).

### **Choice**

Participants indicated that they did not feel they had choice or control over many aspects of therapy including decisions about therapy ending (6, 13); the number of sessions (1, 2, 5); and who attended therapy (4, 6, 10). Some participants did not feel included in the setting up of therapy in terms of session days/times (7), were unhappy with waiting times for therapy (6) and found it difficult if sessions had to be cancelled (2). Participants often did not initially choose to access psychological therapy and were referred by someone other than themselves (13). Although most participants engaged relatively quickly following this referral, for one participant they did not engage as they did not think they needed to change; highlighting the importance of choice in accessing therapy.

## **Group dynamics**

### **Inclusion**

For studies involving group interventions, the relationships which developed amongst group members were important for participants (1, 5, 8, 9, 10) and appeared more helpful than the therapeutic relationship within group interventions. Attending a group with individuals with similar experiences helped participants to feel able to share their experiences as they felt other group members understood their situation and provided support (5, 8, 14, 15). This inclusive nature of the group

contrasted experiences elsewhere, where participants did not feel able to talk as openly for fear of judgement (8).

### **Group composition**

Although the inclusive nature of a group could be helpful, some participants found being in a group environment difficult and described high anxiety about talking or doing practice exercises, such as mindfulness, in a group setting (10, 14, 15, 16). Participants also talked of difficult interpersonal relationships within the group (9, 15) and seemed to struggle if others in the group were dissimilar to them (1, 8, 10). Observing other participants' distress within the group and hearing about their life experiences could also be upsetting for participants (8). For some participants, the presence of their support worker helped them to manage difficult group dynamics (15).

### **The therapeutic relationship**

#### **Positive feelings towards therapist**

A number of participants indicated that they had general positive feelings towards the therapist, describing the therapist as 'nice' and talking of their like of the therapist (2, 3, 6, 7, 11, 13).

#### **Feeling listened to and valued**

As well as general positive feelings towards the therapist, participants indicated that they felt understood and listened to within therapy (2, 3, 4, 8, 12, 13, 15). This is illustrated by one participant who said 'but you can actually see by (therapist) that she's listening, because she's looking straight at you when, when you're talking to her and she just listens as well' (12).

#### **Collaborative**

The findings highlighted how, through the collaborative process of therapy, participants felt treated as an equal, working together with the therapist rather than

the therapist being viewed as the expert (12). Some participants highlighted how they had to put work in themselves to therapy (7), further demonstrating the collaborative nature of their therapy sessions. However, other participants seemed to struggle with the therapist asking questions of them in a collaborative nature (8). Moreover, other participants indicated a dependent alliance with the therapist rather than a collaborative one, 'X sorts my problems out. I've had problems the last three weeks and he wrote them down and sorted it out. I leave it to him to sort things out' (11).

### **The impact of therapy**

#### **Positive impact on life**

Participants saw positive changes in social aspects of their lives and in their emotional wellbeing and behaviour following therapy (2, 3, 4, 6, 7, 9, 11, 12, 15, 16). For instance, one participant illustrated the social gains 'I go out a lot and do things. I do yoga, church and to groups' (6) whilst another highlighted the positive changes to their emotional wellbeing and behaviours, 'and I seem to find I'm feeling a hell of a lot, lot better and happier and I mean I'm not hitting anybody. I'm not falling out with anyone' (12). The positive influence of therapy on relationships was also apparent, with participants noting interpersonal difficulties had reduced following the psychological intervention (6, 9, 16).

#### **Use of new skills**

Participants talked of how they have used some of the skills they learnt through therapy effectively in their daily life (1, 3, 5, 7, 9, 10, 14, 16). One participant illustrated this, '...and I went and walked off to count to ten. I counted to ten in my head (. . .) you got to count to ten in your head and that's what I done (. . .) that's what I done good with that' (9).

#### **Maintaining change**

Although participants reported on how they had effectively used their new skills and strategies outside of therapy, sometimes participants found it hard to use

these skills during difficult situations (1, 4, 9, 13, 15, 16). Furthermore, participants seemed to struggle with their difficulties still persisting after therapy and the time it took to see change (4, 12). For example, one participant reported ‘what was hard like problems in your life, like you’re obsessed with it...won’t fade away easily’ (4). The role of the person with an intellectual disability in maintaining change over time was highlighted, ‘I mean she can give me all the advice in the world cause virtually that’s what she was doing but it was up to me to take on board what she was saying and do something about it myself, so it was all about me’ (2). The importance of a supportive social network for maintaining change outside of therapy sessions was also key for some participants as was the role of the psychologist in facilitating wider changes related to health and social care needs (13, 15).

### **Comparisons across interventions**

There were some differences in themes for individual vs. group interventions. Interestingly, the theme of ‘the therapeutic relationship’ did not arise within any of the included group studies. Participants of group interventions instead highlighted the helpful and unhelpful aspects of the group relationships, rather than the therapeutic relationship. Furthermore, ‘use of new skills’ was mainly identified from group intervention studies.

Although the majority of themes were relevant across therapeutic models, there were some differences. ‘Use of new skills’ arose in studies which involved CBT, DBT and CFT but not in studies using psychodynamic models. The theme of ‘maintaining change’ occurred in studies involving CBT and DBT but did not occur in studies using psychodynamic models. This is not surprising given the emphasis of CBT and DBT in using and practicing new skills outside of therapy.

### **Discussion and recommendations**

This synthesis of 16 papers using a meta-ethnographic approach has identified a number of themes related to experiences of therapy from the perspectives of people with an intellectual disability. Helpful aspects of therapy included: talking about difficulties, confidentiality, adaptations to increase

accessibility, feeling listened to and valued by the therapist, collaboration, inclusive nature of a group environment, the positive impact of therapy on participants' lives, and use of new skills outside of therapy. Challenges of therapy included: anxiety elicited when preparing for therapy, the distressing nature of talking about difficulties, inaccessible session content and homework, and difficulties in maintaining change after therapy has ended.

Although there are some similarities when comparing these findings to the general population, this review highlights a number of challenges and therapeutic dilemmas specific to people with intellectual disabilities and indicates there are significant changes that still need to be made in order to offer people with intellectual disabilities a psychological service that is fully adapted to their needs. Firstly, the theme of 'adapting to therapy' highlights that talking openly within a therapeutic context can be very powerful for people with intellectual disabilities but can also be very difficult and distressing. Difficulties in talking about experiences have also been found in other minority groups. For instance, refugees rarely access mental health services, which is in part likely to be due to stigma of mental health within refugee communities and experiences of abuse of power by those in authority, where sharing personal information with strangers could place people at risk of violence (Ellis et al., 2011). There is extensive research illustrating the social exclusion of people with intellectual disabilities (e.g. Hall, 2005). Given these experiences, people with intellectual disabilities may not have had many previous opportunities to talk about themselves and their feelings. This limited experience of self-disclosure may make talking more distressing for people with intellectual disabilities and could also explain the anxiety experienced by participants prior to commencing therapy. These findings suggest that currently there is not enough support given to setting up therapy for people with intellectual disabilities and preparing them for what therapy may involve. Consideration should be given to this by clinicians in the future when they begin to work therapeutically with a person with an intellectual disability. This also has potential implications for services, such as Improving Access to Psychological Therapies (IAPT) and adult mental health services, who should where possible be making 'reasonable adjustments' so that people with intellectual disabilities can access these services (Department of Health, 2009). It is therefore extremely important that these services are aware of these

challenges and recommendations in terms of setting up therapy for people with intellectual disabilities.

Furthermore, the theme of ‘group dynamics’ showed that a group environment could be experienced as inclusive and beneficial, as contact with those with similar difficulties can provide some comfort. The usefulness of this inclusive group environment was focused on more than the relationship with the therapist in group intervention studies. This highlights the importance of validating and normalising peer experiences for people with intellectual disabilities but exposure to such experiences is often very limited for this client group. This is further supported by qualitative research showing the importance of talking to others and being accepted for people with intellectual disabilities (Abbott & Mcconkey, 2006). Exposure to those with more significant needs can also be an unwanted, distressing mirror to people’s own difficulties. Given people with intellectual disabilities’ limited experiences of self-disclosure, they may not be prepared for the level of distress and disclosure that they may hear within a group environment. This again shows the importance of spending time preparing participants for the nature of a group environment and the potential distressing events others may discuss within the group so people with an intellectual disability are more informed and can make an informed choice before participating in a group intervention.

Although adaptations increased engagement in therapy, participants struggled to apply the content of sessions to everyday life and to maintain change outside of therapy. This raises the question as to how truly accessible therapy is for people with intellectual disabilities. Guidelines suggest that written summaries and regular feedback on sessions to family members or support workers may be helpful to support the implementation of strategies outside of therapy (BPS, 2015). However, given that confidentiality enabled participants to share more openly with their therapist, this highlights a dilemma in terms of how much the wider system should be involved in therapy and how this is managed if the client does not want members of their system to be included. The findings suggest that current adaptations to therapy are not of an acceptable level and further, individually-tailored work is needed to support people with intellectual disabilities to fully understand session content and to maintain long-term changes following therapy whilst still being sensitive to the dilemma of how much to involve a person’s wider



system. Moreover, participants shared concerns about what was being shared with their wider network and did not feel included in decisions about the therapeutic environment, indicating that they may have felt powerless and as if they had no control in terms of the knowledge shared with their wider system or over the therapeutic process. These findings illustrate that there are still improvements needed in order for people with intellectual disabilities to feel empowered, fully included and equal within the therapeutic environment.

It is interesting that within this review there was less focus on unhelpful aspects of the therapeutic relationship in comparison to the general population. Power could provide one possible explanation as to why participants with an intellectual disability may feel less able to express any difficulties within the therapeutic relationship. Further research is needed to ensure evidence-based pathways are developed through which people with intellectual disabilities feel able to share difficulties within the therapeutic relationship. Research using single case experimental designs to gather feedback on a session by session basis may provide more opportunities for people with intellectual disabilities to express what was particularly helpful or unhelpful within the therapeutic relationship during a particular session, an approach which has been used in the general population (Martin, Garske, & Davis, 2000). However, it is important to consider whether people with intellectual disabilities would feel able to give honest feedback if asked to do so at the end of a session by their therapist. Interviews with someone other than the therapist at regular time points during therapy could overcome this and allow for more detailed feedback on therapy sessions. The review also raises recommendations for researchers within this field. In particular, researchers should ensure they clearly document consent procedures and how they considered the researcher-participant relationship.

There are some limitations to the current review. Firstly, although the majority of included studies used interviewers who were not known to the participant, these interviewers may still have been perceived as working within the service (e.g. trainee clinical psychologists). This may have influenced participants' responses, especially in relation to challenging aspects of therapy, and the majority of papers did not explicitly state how this researcher-participant relationship was considered. Moreover, studies included in this review tended to involve people who

had participated in therapy for a set number of sessions (e.g. minimum of 6 sessions). This excluded participants who had dropped out of therapy at an early stage, who may have had less helpful experiences of therapy, and so this may have biased the findings of this review. Gathering qualitative feedback on a session by session basis would enable the views of participants who have dropped out of therapy to be captured and may provide valuable information as to why people with intellectual disabilities leave psychological therapy. Furthermore, the number of sources contributing to each theme was small in comparison to the overall sample size of sixteen included studies, although each of the presented themes were derived from a minimum of four sources. In summary, this review has identified a number of helpful and unhelpful aspects of psychological therapy specifically for people with intellectual disabilities. The findings indicate that there are significant changes that still need to be made in order to offer people with intellectual disabilities a psychological service that is fully accessible and adapted to their needs. In particular, more consideration is needed of power differentials within the therapeutic relationship and further thought given as to how people with intellectual disabilities can feel empowered, fully included and equal within the therapeutic environment.

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### Appendix 1

